

**MINUTES
of the
SECOND MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**September 9, 2014
Barbara Hubbard Room, Pan American Center
New Mexico State University
Las Cruces**

The second meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee (LHHS) was called to order by Representative Doreen Y. Gallegos, chair, on Tuesday, September 9, 2014, at 9:15 a.m. in the Barbara Hubbard Room of the Pan American Center at New Mexico State University (NMSU) in Las Cruces.

Present

Rep. Doreen Y. Gallegos, Chair
Sen. Nancy Rodriguez, Vice Chair
Sen. Craig W. Brandt
Rep. Nora Espinoza
Sen. Linda M. Lopez
Rep. James Roger Madalena

Absent

Advisory Members

Rep. Phillip M. Archuleta
Rep. Edward C. Sandoval
Rep. Elizabeth "Liz" Thomson

Rep. Miguel P. Garcia

Guest Legislators

Sen. Howie C. Morales
Sen. Gerald Ortiz y Pino
Sen. Mary Kay Papen
Sen. William P. Soules

Staff

Shawn Mathis, Staff Attorney, Legislative Council Service (LCS)
Michael Hely, Staff Attorney, LCS
Rebecca Griego, Records Officer, LCS
Nancy Ellis, LCS

Guests

The guest list is in the meeting file.

Handouts

Copies of all handouts are in the meeting file, including those from public comment.

Tuesday, September 9**Call to Order and Introductions**

Representative Gallegos welcomed those assembled and asked subcommittee members and staff to introduce themselves. She then introduced Garrey E. Carruthers, president of NMSU and former governor of New Mexico.

Welcome

President Carruthers welcomed the subcommittee to the NMSU campus and described several recent developments, including near-completion of construction on a nondenominational spiritual center funded by a private donation, as well as the upcoming grand opening of Pete V. Domenici Hall, which will house the Domenici Institute for Public Policy. President Carruthers also described plans for a privately funded \$26 million College of Osteopathic Medicine to be located at NMSU. While the college will be privately owned and operated, its students will pay full student fees and become an integral part of the campus. Osteopathic medical schools tend to produce more primary care doctors, which are in short supply in New Mexico, President Carruthers noted, and similar privately owned schools are already operating at Auburn University and Virginia Tech. A full presentation about plans for the new osteopathic college will be made at tomorrow's meeting of the LHHS.

Southern New Mexico Provider Panel Update

Pam Lillibridge, chief executive officer (CEO) and president, Tresco, described her organization as a nonprofit based in Las Cruces that has provided supports and services for developmentally delayed or disabled children and adults in southern New Mexico for more than 30 years. The success of agency programs is not in doubt, Ms. Lillibridge asserted, but their sustainability is. Tresco struggles to keep and retain staff despite the small increase in Family Infant Toddler (FIT) program provider rates, with competition for providers coming from public schools and other government entities. Ms. Lillibridge also held up a two-inch-thick, 268-page stack of state regulations and standards with which the agency must comply — up from just 49 pages in 1998. Health insurance costs for her organization increased by 40 percent last year, she said, and the transition to Centennial Care (CC) has been rocky. Ms. Lillibridge touted the success of Tresco's supported employment programs, but she said her organization has been challenged by lowered reimbursement rates for these programs. She urged the state to revisit rates and standards and to look at which programs actually work.

Evangeline H. Zamora, CEO, Life Quest, Inc., described her organization, a community-based nonprofit that has provided services to individuals and their families with or at risk for developmental disabilities for more than 35 years. Life Quest is based in Silver City and serves Grant, Luna, Hidalgo and Catron counties. Ms. Zamora described grave difficulties for the

organization, which began to see declines in revenue in 2012 following changes in rates and difficulties with the new Supports Intensity Scale (SIS) assessment. As a consequence, her board of directors decided to eliminate supportive living services, along with initiating salary cuts, benefits reductions, elimination of raises and the layoff of 20 employees. Therapists often have to travel a long way, sometimes as many as four hours, for one hour of reimbursement, Ms. Zamora said, and she would like to echo Ms. Lillibridge's comments that this system is unsustainable. Both CEOs lamented the delay of the rate increase for service providers on the Medicaid developmental disabilities (DD) waiver. FIT providers were given a raise, but DD waiver providers are still waiting, they said.

Peggy Denson-O'Neill, CEO, Zia Therapy Center, Inc., described her organization, which is based in Alamogordo and has provided services in Otero County for 54 years. Ms. Denson-O'Neill also described financial difficulties for her organization and problems with hiring and retaining employees. Zia can no longer afford to provide insurance for employees, she said, and while her organization used to have a very experienced staff, this is no longer true; the result is what she described as an alarming loss of institutional memory. In Zia's FIT program, there has been reduced revenue, coupled with increased unfunded mandates from the federal Patient Protection and Affordable Care Act and Race to the Top, and the difficult proposition of an increased minimum wage statewide. The DD wait list is a problem, she said, but the system cannot provide the services and centers will continue to close. Ms. Denson-O'Neill sounded an alarm to subcommittee members: rate increases for providers are crucial to the survival of services in New Mexico.

On questioning, Ms. Lillibridge, Ms. Zamora, Ms. Denson-O'Neill and subcommittee members addressed the following topics.

How to convey the critical nature of this issue to the Legislative Finance Committee (LFC). A member commented that unless rate increases are in the budget, nothing will happen. Ruby Ann Esquibel, principal LFC analyst, who was in the audience, responded that a one-hour hearing on the Department of Health (DOH) budget preview is scheduled for October 30 at 12:30 p.m. at the State Capitol, and all are invited to attend. Members agreed that more than five minutes in front of the LFC would be required to make a persuasive case for rate increases, and they urged Ms. Esquibel to take their concerns back to the LFC director. Ms. Esquibel said rate increases are part of the DOH budget, but another member cautioned that if the increase is part of the DOH budget, money likely will not get to where it needs to go. A guest legislator agreed with members' concerns and urged a more formal request to the LFC in the form of a letter. A motion was made, seconded and passed unanimously to send a letter from both this subcommittee and the LHHS chairs and vice chairs to request time for this issue to be presented to the LFC.

The burden of increased regulation. Ms. Lillibridge explained that the stack of papers she held up for subcommittee members represents state service standards for providers; it is equivalent to a day-to-day operations manual, she said. The standards, which also are used by

the Quality Management Bureau of the DOH to evaluate providers, have increased tenfold since 1998.

Where is the \$500,000 appropriated for DD waiver provider rate increases by July 1? Cathy Stevenson, deputy secretary, DOH, speaking from her seat in the audience, said that those DD provider funds are part of the complex Medicaid budget, and because of information technology (IT) difficulties and the need for federal approval, the funds have not yet been released. The delayed provider rate increases are expected to be released in October or November, Ms. Stevenson said, and they will be retroactive to July 1.

What happened to clients whose services have been eliminated? Ms. Zamora said that some Life Quest clients were picked up by a for-profit agency in Grant County, but there were folks being served under the state general fund that were not picked up. For clients on DD waiver services, some may have to move to other counties in order to continue to receive services, she said.

The chair thanked the panel presenters, adding that she felt subcommittee members needed to hear the realities facing these providers and hear about services that already have been dropped.

Navigating Autism Services in Southern New Mexico

Abel Covarrubias, CEO, Aprendamos Intervention Team, and board chair and co-founder, Hearts for Autism Fund, provided some statistics for autism, which is five times more likely to occur in boys than girls and usually becomes evident before the age of three. Autism has a huge economic impact, Mr. Covarrubias said, with costs estimated at \$17,000 annually to care for a child with autism and overall costs to society of \$11.5 billion each year. It takes four to six months to get an evaluation for a child under three years old, he said, and for children over age three, there is a nine-to-12-month wait list at the University of New Mexico (UNM). There is a limited number of psychologists who are qualified to diagnose autism, Mr. Covarrubias said, and he would like to see additional funding for more teams at a local level to diagnose and provide early intervention services.

Marisa Cano, Hearts for Autism Fund board member, parent liaison, teacher and the parent of two children with autism, said she knows first-hand the many challenges of diagnosis and treatment. Some families have a diagnosis from a neuropsychologist, but they lack the full workup and evaluation required by schools in order to tailor services, she said. Behavior therapy teaches functional skills in order for a child to become productive and to engage with family and society. Parents with Medicaid have better access to services with no co-pay, but insured children often do not get services because co-pays are a barrier. Ms. Cano said she was doing initial visits with families, planning to hand them off to other resources, but those have not materialized under CC, nor under private insurance, either. She has had to make the decision for her family to stop working in order to care for her children, but then her family no longer has the financial resources to pay for therapy. Under CC, everything has come to a standstill, Ms. Cano said, because the guidelines for autism spectrum disorder are not available.

Michael Gutierrez, certified applied behavior analysis (ABA) therapist, said he helps to identify children's deficits and address these deficits with new adaptive skills. ABA is an intense and specialized therapy for young children and has shown a success rate of 50 percent who can enter a regular kindergarten classroom, Mr. Gutierrez said. While there are thousands of certified ABA therapists nationwide, there are only 25 to 30 such therapists in New Mexico, and more need to be brought into the state. Early intervention can decrease the average lifetime cost of \$2.4 million per person by two-thirds, Mr. Gutierrez asserted.

A member asked what would be needed to create a local team. Mr. Covarrubias explained that there are specific criteria about which professionals should be on such a team. If funding were to become available, his board would locate the appropriate staff for the program. Ms. Cano agreed that the community desires a local option; not everyone can afford the travel to UNM or the co-pays for evaluations. The presenters said they want to put funding for a Las Cruces center on the legislators' radar and also to ask that consumers and providers be included on the state's Autism Coordination of Care Council, which now consists only of representatives of managed care organizations and state agencies.

Tour of Speech and Hearing Center/Luncheon Presentation on NMSU Cleft Palate and Rural Outreach Programs

Hearing loss in New Mexico adults and children has many different causes, and the Edgar R. Garrett Speech and Hearing Center at NMSU has remained dedicated for more than 60 years to providing cutting-edge diagnoses, treatments and services. During a luncheon tour, subcommittee members were introduced to staff and to several state-of-the-art instruments used in the clinic, and introduced to a group of consumers and family members who provided heart-rending accounts of successful treatment and excellent follow-up from staff at the center. The ultimate goal for the center's consumers of all ages is independence.

A PowerPoint presentation by the Department of Special Education and Communication Disorders during lunch highlighted NMSU's Cleft Lip and Palate Center (see handout), which provides surgery and follow-up speech and dental services for approximately 50 cases a year, as well as clinical training for graduate students. Arrowhead Medical Academy, a satellite facility for the speech and hearing center, will open in October, providing hearing aid services to the community for the first time in a corporate partnership with ReSound. The presentation also described autism services and research, with NMSU providing assistive technology for classroom instruction and teacher training for a graduate certificate in autism. The autism program aims to improve screening and early diagnosis and to create statewide clearinghouses and conferences to disseminate information on evidence-based practices to schools, parents, caregivers and other interested parties.

DOH Update: DD Waiver Wait List; SIS; Provider Rate Increases; Vacancy Rates

In response to a request from the subcommittee's chair and vice chair for up-to-date information on the above topics, Ms. Stevenson provided information to members (see handout) with current details on the Medicaid DD waiver program. As of June 30, 2014, there were 3,988

individuals being served on the DD waiver, and an additional 601 individuals were enrolled in Mi Via (self-directed services), bringing the total to 4,589, Ms. Stevenson said. As of August 15, 2014, there were 6,052 individuals on the DD central registry (wait list), broken down as follows: 1,404 in "start" status (new applications), 696 in "pending" status (eligibility not yet determined), 397 in "allocation on hold" status and 3,625 in "completed" status. Ms. Stevenson also presented a draft spreadsheet (not yet vetted with Medicaid) showing program costs, allocations and reversions for fiscal year (FY) 2014 and projections through FY 2016. The program reversion to the general fund for FY 2014 is \$6,863,509. This number is projected to be \$1,830,766 for FY 2015, while a shortfall of \$4,472,076 is projected for FY 2016, which Ms. Stevenson said she was confident could be covered by changes within the DOH. The DD waiver program budget is over \$102 million. Ms. Stevenson noted that the DD waiver wait list is down for the first time, and she said the DOH goal is to at least keep even.

Several pages of Ms. Stevenson's handout detailed increased rates (ranging between 1.5 to three percent) for customized in-home support, supported living and customized community support groups, as well as rate increases in FY 2015 for some individual supported employment (see handout). The DOH will continue to work with stakeholders and Medicaid on the best systemic approach to address needs on a long-term basis, she said. Ms. Stevenson reiterated that the reason additional funding approved by the legislature last year to increase DD waiver provider rates has not yet been distributed is due to IT problems, but these will be resolved no later than November, and rate increases will be retroactive to July 1, 2014.

Regarding questions about additional staffing needs, Ms. Stevenson said that in recent years, funding for services has grown, but funding for system development and staff has not. She asserted that current language in the state budget does not provide the flexibility needed to address provider and staff capacity. Allowing flexibility in the use of funds that cannot be spent for direct service or appropriating available funds more purposefully across budgeting categories would assist the DD waiver program to operate more effectively.

Lastly, Ms. Stevenson provided members with a graph of DD waiver consumers in each of the SIS group categories (A through G) utilized to determine levels of service need (see handout). The total number of individuals who have been given the SIS assessment is 3,895. Ms. Stevenson said that New Mexico contractors, rather than out-of-state contractors, are now being utilized to conduct the assessments, and the DOH has been working closely under a contract with UNM on training.

On questioning, Ms. Stevenson and subcommittee members addressed the following topics.

Why has the DOH not asked for additional funding to reduce the DD wait list? Ms. Stevenson said that this decision is an administrative one and is an effort to manage the program with resources already in place. Ms. Stevenson denied that the current 15 percent vacancy rate in the department is a factor in not moving more people forward onto the waiver. Last year, 418

individuals were brought into the program, she noted, with this number including the 70 who replaced individuals already on the waiver who died or moved out of state. A member noted that moving 300-plus persons off the list each year does not seem like a strategy. Ms. Stevenson responded that the state cannot spend more money than it has in the budget. She confirmed that the DOH's FY 2016 budget request of \$102 million for its Developmental Disabilities Supports Division does not include any new funding to take individuals off the wait list onto the waiver, noting that capacity is an issue. If there are not enough providers to deliver more services, the services will not happen, she said. The division has been meeting with providers, Ms. Stevenson said, and plans to return to an hourly calculation for rates rather than the current 15-minute measure, which has been difficult for providers. She agreed that increased documentation has become a burden to providers, and she said one of her staff is currently working to simplify and streamline the department's regulations. Ms. Stevenson said the DOH would be supportive of an independent rate study, but she cautioned that funding not be given to the department for this, as the study would immediately become suspect. A member expressed disappointment that departments continue to bring in flat budgets and said there does not appear to be much commitment to the DD community. Ms. Stevenson responded that the DOH is committed to take whatever funds are available and to use whatever flexibility it is given to get DD consumers off the wait list and into services.

Questions about reassessment and changes to SIS scores. Ms. Stevenson said that all adults on the DD waiver have received an SIS assessment. Looking at the graph she provided, a member noted that it looked like a bell curve instead of individualized assessments. Ms. Stevenson said she would expect this type of distribution, and she noted that before the SIS, there was an annual resource assessment for each consumer. The department is trying to be a better steward of the money, she added, and now some services require preauthorization. Under questioning, Ms. Stevenson estimated that between 650 and 700 SIS reassessments have been completed, but she did not have these exact numbers, nor numbers of how many scores changed to a higher level of need. Six months ago, the figure was high — about 70 percent, she said. The first SIS costs \$850, and the reassessment is a higher cost, but Ms. Stevenson did not have those figures available.

Comparison of services and provider rates to those in other states. Ms. Stevenson said rates are higher in New Mexico, but it is very difficult to compare services and rates nationally. New Mexico offers more services than many other states, and new services have recently been added. She reiterated her support for an independent rate study.

Public Comment

Doris Husted, public policy director for the ARC NM, mother of a DD waiver consumer and chair of the Central Registry Subcommittee (formerly the Senate Memorial 20 Task Force), which is working on a plan for the state to move people off the waiting list into services, told members that increasing capacity is not just a DOH issue. The Human Services Department and its Income Support Division (ISD) are involved, and there has to be capacity at the ISD for

processing certifications, she said. Funding to keep staff is critical, because if staff changes every few months, quality of services will suffer. Long-term relationships are paramount.

Carol Bernstein, a parent advocate, said the system is not working. The SIS was originally intended to assess ability, not to be paired with funding. Once a certain score is achieved, that is the level of funding unless damage can be shown. Therapy is gone, gains are lost and everything is a bigger mess, she said. The department says people are not complaining: half of these folks do not have a place to work, do not have command of the English language and often have no guardian. Ms. Bernstein questioned the role of the SIS in reducing the wait list and asked if it is worth it.

Jim Jackson, executive director of Disability Rights New Mexico, summarized today's testimony: providers need rate increases and yet the DOH has not asked for a single penny for this. There is no push by the DOH to get people off the wait list into the waiver, no plan to make any progress with the wait list and no new money requested. It feels like we are in exactly the same place as last year, he said. There have been complaints, and his organization has been in federal district court with eight families on specific issues, including problems with fair hearings; a ruling is expected later this year. Mr. Jackson advised legislators to insist on regular data from the department and to pass a bill directing the department to come up with a plan and budget to reduce the DD wait list.

Maureen Grant, an employee of Tresco, said access to care for those with disabilities is a continuing challenge in Las Cruces. Someone who was getting 30 to 40 hours of service now cannot get help to go to the doctor because hours have been reduced. Moving forward, the aging population will need more support and help paying for medications.

Anna Otero Hatanaka, executive director of the Association of Developmental Disabilities Community Providers, reminded the subcommittee that her members are still desperately awaiting the small rate increase promised to them starting July 1. She urged that last year's \$500,000 for FIT provider rate increases and the \$500,000 for DD waiver providers become an annual part of the DOH budget. It is not fair to compare New Mexico rates to other states because New Mexico is one of the few states that does not have public institutions, so outpatient rates appear more costly.

Al Sanchez said he has spent 27 years working in supported employment. Lives are being changed for the better with a dedicated direct care staff, he said, but fair compensation is a critical issue. Staff needs to be compensated fairly. This is an economic issue, he said: jobs can be created by serving these individuals.

Wes Jackson, president of the student body at NMSU, told the subcommittee that paratransit services for students with disabilities have been outsourced to the City of Las Cruces and are working well. It is hoped that the program can be expanded in the future.

Adjournment

There being no further business, the subcommittee adjourned at 4:00 p.m.